# How This Guide Can Help You Help Others

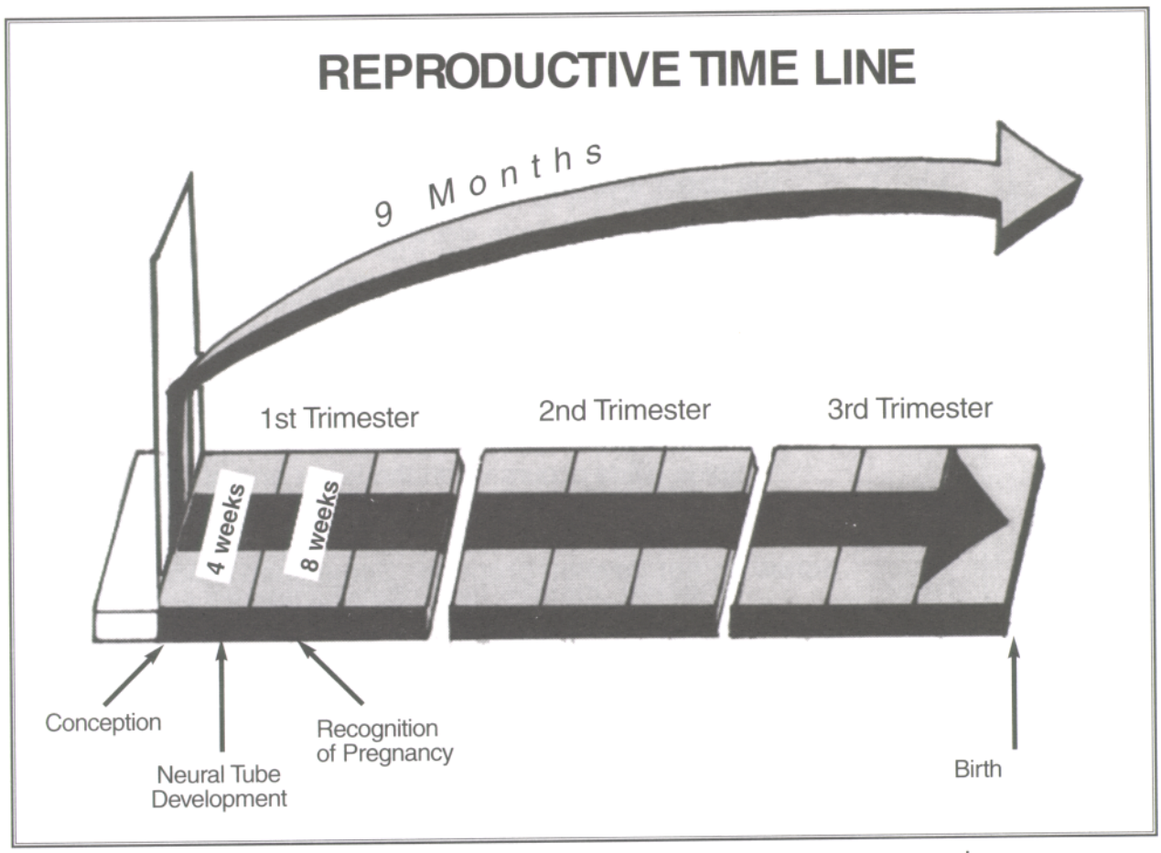
You can take many different approaches to increasing the number of childbearing-age women in your community who consume enough folic acid each day to minimize their risk of having a child with an NTD (neural tube defect). *Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide* demonstrates how you can design, develop, deliver, and evaluate a birth defects prevention program. The accompanying appendices, provided on diskette, include sample materials such as cover letters, news releases, public service announcements, tested survey questions, and other tools for you to use or adapt in conducting your program. The glossary, Appendix A, is also printed at the end of this text for your reference. Throughout the guide are examples of real-life folic acid campaigns to spark your creativity in developing each step of your community's program. Both the sample materials on the diskette and the real-life examples should help you to design and carry out your program.

This guide's step-by-step process can also help you to design, develop, deliver, and evaluate other public health awareness campaigns and birth defects prevention programs in your community. If you have any questions about this guide, please call (770) 488-7160 or send an e-mail to **flo@cdc.gov**.

# How Folic Acid Can Prevent Some Birth Defects

By educating women about the importance of folic acid and encouraging them to increase their intake, your community can have a direct effect on the lives of families and the health of their babies. Birth defects of the spine and brain can cause severe disabilities or death. Each year, approximately 4,000 pregnancies in the United States are affected by a defect of the spine (spina bifida) or brain (anencephaly), also known as NTDs (neural tube defects). The B-vitamin folic acid can help to prevent 50 to 70 percent of these birth defects every year.[1] However, most women do not consume enough folic acid daily to protect against these serious birth defects. Public health education about folic acid is just beginning.

To get the recommended amount of folic acid each day, most women will need to change their behaviors either to take vitamin supplements that contain folic acid or to consume sufficient amounts of breakfast cereals and other foods fortified with folic acid. This guide provides ways for you to increase the knowledge of reproductive-age women regarding the need to consume adequate amounts of folic acid. With that knowledge, they can maximize their chances of having a healthy pregnancy and minimize their chances of having a baby born with one of these serious birth defects.

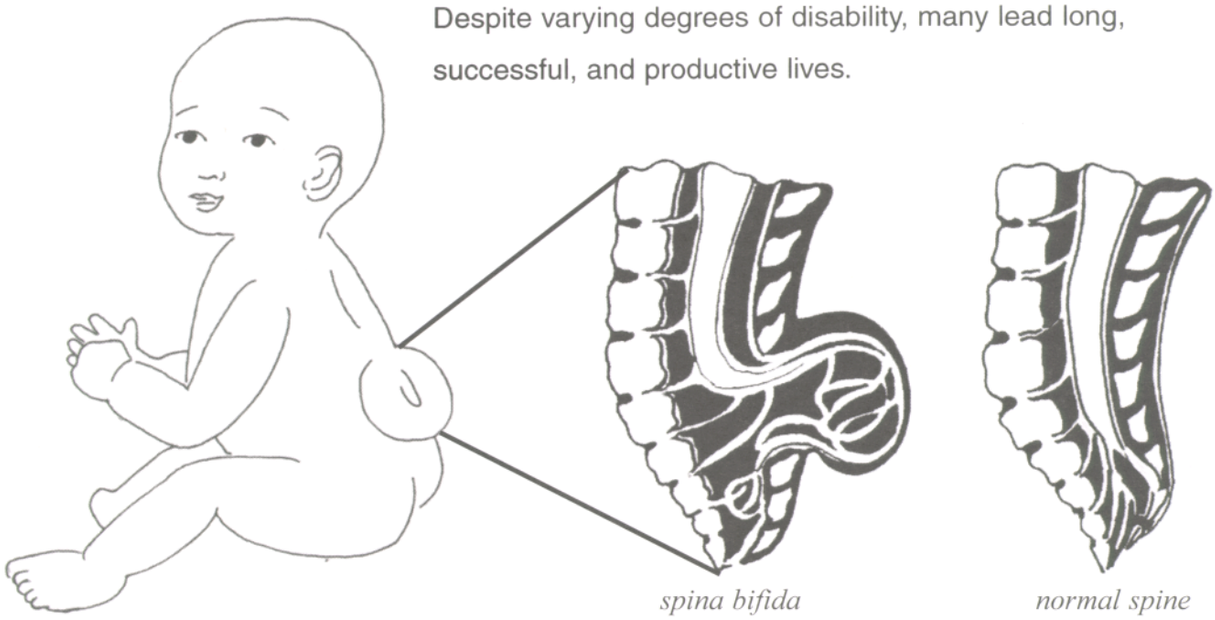



## About NTDs

NTDs (neural tube defects) are birth defects that occur very early in pregnancy. The defects develop between the 17th and 30th day after conception (four to six weeks after the first day of a woman's last menstrual period), usually before a woman knows she is pregnant. During this critical time of pregnancy, the proper formation and closure of the neural tube, which later becomes the spinal cord, brain, and bone surrounding the spinal cord and brain, normally takes place. An NTD occurs when the neural tube fails to close properly.

**Anencephaly** and **spina bifida** are the two most common NTDs. *Anencephaly* is a fatal condition in which the upper end of the neural tube fails to close. In these cases, the brain fails to develop completely or is entirely absent. Pregnancies affected by anencephaly often result in miscarriages, and the infants who are born alive die very soon after birth.

*Spina bifida* occurs when the lower end of the neural tube fails to close. As a result, the spinal cord and back bones do not develop properly. Sometimes a sac of fluid protrudes through an opening in the back, and often a portion of the spinal cord is contained in this sac. Paralysis of the infant's legs, loss of bowel and bladder control, hydrocephalus ("water on the brain"), and learning disabilities are often associated with spina bifida. Eighty to 90% of infants born with spina bifida survive. Despite varying degrees of disability, many lead long, successful, and productive lives.



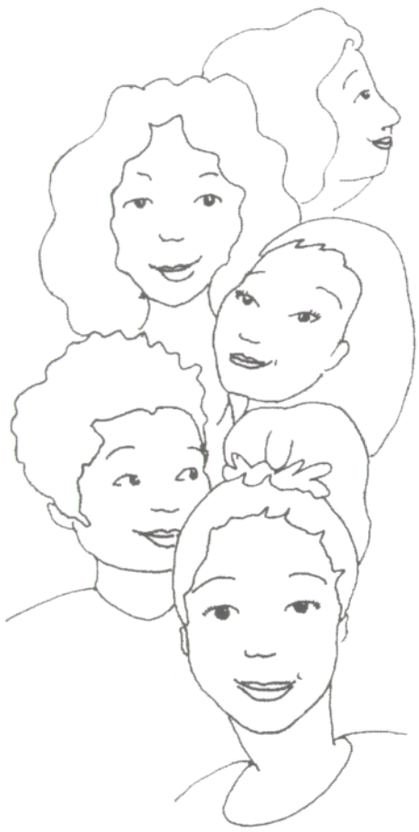
*spina bifida* *normal spine*

## What Is it Like to Live With an NTD?

Both prevention and treatment of NTDs—spina bifida and anencephaly—are important. NTDs impact not only the life of a child and those of his or her family, but the community as well. As a child with spina bifida grows older, he or she faces unique economic, educational, medical, health, and emotional issues. Paralysis of the legs and bowel and bladder management problems are common for those with spina bifida. These problems may affect a person's health, self esteem, personal interactions, and work and recreational opportunities.

Despite physical and mental challenges, many people with spina bifida live independently. Today, mental retardation caused by hydrocephalus, a complication of spina bifida, is uncommon because of early medical and surgical treatment. However, learning disabilities are common. Although medical care has greatly improved the survival rates and quality of life of children with spina bifida, the children and families affected live with varying degrees of physical and social challenges for life. Additional references on neural tube defects and a list of supportive organizations for parents and children affected by spina bifida are included in Appendix B.

## Who Is at Risk for Having a Baby With an NTD?



*Any woman who is capable of becoming pregnant could have an NTD-affected pregnancy.*

There are approximately 60 million women of childbearing age in the United States. Any woman who is capable of becoming pregnant could have an NTD-affected pregnancy. It is not possible to predict which women will have a pregnancy affected by an NTD. Ninety-five percent of women with NTD-affected pregnancies have no personal or family history of NTDs. However, some risk factors are known. These include:

- A previous NTD-affected pregnancy. (This increases a woman's chance of having another NTD-affected pregnancy by approximately 20 times.)
- Maternal insulin-dependent diabetes.
- Use of anti-seizure medication. (Valproic Acid/Depakene® and Carbamazapine.)
- Medically diagnosed obesity. The body-mass index is used to determine obesity. (For more information on this measurement, see http://www.nhlbi.nih.gov/nhbli/cardio/obes/prof/guidelns/ob_home.htm)
- Exposure to high temperatures in early pregnancy. (For example, prolonged high fevers and hot-tub use.)
- Race/ethnicity. (NTDs are more common among white women than black women and more common among Hispanic women than non-Hispanic women.)
- Lower socio-economic status.

Appendix C contains a list of health care professionals and organizations that can provide advice and assistance on these issues.